Progress, Benefits, and Challenges in Measuring Public Opinions about Stuttering Worldwide

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I. Introduction and rationale
   A. International Project on Attitudes Toward Human Attributes (IPATHA)
      1. Originally: International Project on Attitudes Toward Stuttering (IPATS)
      2. Potential: for other attributes besides stuttering
         a. Mental illness
         b. Obesity
         c. Alcoholism, etc.
   B. Goals for today
      1. An attitude exercise
      2. Describe IPATHA initiative, rationale, and goals
      3. Status report
         a. Snapshot of results from pilot studies
         b. Methodological issues and sample data
      4. Summary: progress, benefits & challenges
   C. Rating exercise
      1. Fill out the small questionnaire
      2. Rate the following animals
         a. Cat: average house cat
         b. Bird: average bird
         c. Snake: small and not poisonous
         d. Dog: average and not barking
         e. Spider: small and not poisonous
      3. What are your attitudes?
         a. Was there a difference between “overall impression” & “wanting to be close to”?
            (1) Which was highest?
            (2) Which was lowest”
            (3) Did your highest get higher?
            (4) Did your lowest get lower?
      4. A public education campaign to improve attitudes toward snakes and spiders
         a. How would I know if I changed any attitudes?
         b. How would I know which techniques or activities were most effective?
   D. Some stuttering facts…
      1. Typical stuttering is physiological
      2. About 50% have genetic evidence
      3. Nonstuttered speech not quite normal
      4. Sex ratio of 3 or 4 males to 1 female
      5. Brain differences in stuttering
      6. Less left hemisphere dominant
      7. Auditory systems function differently
      8. Temperament and language differences documented
   E. Then why study attitudes?
      1. Would you be comfortable around—or concerned if your neighbor…
         a. Stuttered?
         b. Was moderately hard of hearing?
         c. Was left handed?
         d. Was an alcoholic?
         e. Had HIV / AIDS?
         f. Was mentally ill?
         g. Was obese?
      2. If you (and most people) were concerned, would the neighbor (and most others with the condition)…
         a. Feel good about themselves, aside from the problem?
         b. Be likely to talk about it openly?

c. Be expected to function normally at school or work?
d. Experience stigma and discrimination?

F. Public attitudes toward stuttering
1. Inaccurate information about its nature
2. Uncertainty about cause
3. "Stuttering stereotype"
a. Stutterers are considered to be shy, fearful, nervous, weak, not assertive, introverted, etc.
b. Stuttering reflects psychological problems

G. Public education campaigns for stuttering
1. Assumption: accurate information will result in greater sensitivity
2. Some problems
a. Can negative attitudes be improved?
b. What works? What does not work?
c. Do some cultures stigmatize stutterers more than others?

H. IPATHA objective
1. Develop instrument to measure public opinion (attitudes) worldwide
a. Public Opinion Survey of Human Attributes-Stuttering (*POSHA-S*)
(1) Detailed information on stuttering and other attributes
(2) Stuttering compared to positive, neutral and negative attributes (anchors)
(3) Relevant demographic information

II. Questionnaire development

A. Task force principles for *POSHA-E* (experimental versions of *POSHA-S*)
1. Consistent with epidemiological principles
a. Population—not individual—attitudes
2. Have acceptable reliability and validity
3. Be short and user-friendly
a. Start with many items; later reduce number
4. Be translatable to any written language
5. Provide representative results

B. Findings from several experimental prototypes of *POSHA-E*
1. Prototypes of *POSHA-E*
a. 1st: Quasi-continuous: respondents drew vertical lines through horizontal line marked at ends and middle
(1) Not user-friendly
(2) Measured with rulers and scored 0-100
(a) Tedious and time consuming
(3) Too many respondent errors
(4) But…did not systematically affect group results!
b. 2nd: 1-9 equal-appearing interval (EAI) scales with "?" for "I don't know"
(1) Converting to 0-100, compares closely to quasi-continuous scale
c. 3rd: 1-5 EAI scales for general and demographic section items; "Yes," "no," "not sure" for detailed section
(1) 1-9 scales: most respondents selected 1, 5, 9
(2) Suggested 1-5 scale adequate where individual differences required
(3) 3-item scale faster and easier to complete
(a) Epidemiological purpose: focus on sample / population trends—not individuals
(b) Treated as EAI in analysis: No = 1, not sure = 2, yes = 3
(c) Compares very closely to previous scales
d. All results: results converted to -100 (negative) to 0 (neutral) to +100 (positive)
2. Pilot study: order effects (St. Louis, Lubker, Yaruss, Adkins, & Pill, 2008)
a. Systematic counterbalancing in first *POSHA-E*
(1) General Section: 4 items with stuttering + 8 anchors
(2) Stuttering 1st, 5th, or 9th
(3) 3 detailed sections: stuttering plus 2 others
(4) Stuttering 1st, 2nd, or 3rd
(5) All combinations of the above (504 orders!)
b. Virtually no order effects noted in results (St. Louis, Lubker, Yaruss, Adkins and Pill, 2008)
c. Item changes
(1) Few questions badly worded

(a) E.g., "How does stuttering affect people's ability to…make friends?" (from "very negatively" to "very positively")
(b) Many marked the middle of the scale for "It doesn't affect" or "doesn't matter"
(c) Some pilot data lost

(2) A few new ideas (questions) emerged
(a) Simplified living situation, health, and vocation items
(b) Added family/country income items
(c) Added personal helping item
(d) Added completion time
(e) Experimented with person values items

3. Examples of *POSHA-E* results from 12 samples (See References *)
   a. Five samples in English
      (1) Durban, South Africa (n = 45; M:F = 33%:67%)
      (2) Copenhagen, Denmark (n = 31; M:F = 45%:55%)
      (3) Ottawa, Canada (n = 30; M:F = 55%:45%)
      (4) Kathmandu, Nepal (n = 40; M:F = 78%:22%)
      (5) Baltimore, USA (n = 21; M:F = 5%:95%)
   b. Five samples in other languages
      (1) Sao Paulo, Brazil (Portuguese) (n = 188; M:F = 35%:65%)
      (2) Douala, Cameroon (French) (n = 33: M:F = 75%:25%)
      (3) Eskisehir, Turkey (Turkish) (n = 106; M:F = 29%:71%)
      (4) Moscow, Russia (Russian) (n = 85; M:F = 15%:86%)
      (5) Kuwait City, Kuwait (Arabic) (n = 424: M:F = 38%:62%)
      (6) Two additional groups in English in search of a "gold standard" for stuttering attitudes
         (a) Board Recognized Specialists in Fluency Disorders (n = 21; M:F = 22%:78%)
         (b) Stutterers who are leaders in the stuttering self-help or support movement (n = 25; M:F = 72%:28%)
   c. Items are from the final version of the *POSHA*
      (1) Illustrates differences among & within samples
      (2) Samples here DO NOT reflect each country's attitudes
      (3) Other samples have been/would be different!
      (4) Most items: fluency specialists and self help leaders had most "positive" attitudes
         (a) Few exceptions
      (5) Least "positive" attitudes most frequently from Nepal (English) and Cameroon (French) but exceptions

C. *POSHA* Summary Profile
   1. Layout: Radial graph showing:
      a. Subcores
      b. Components (3-4 in each subscore)
      c. Item clusters (several in each component—not shown)
   2. Subscores and components
      a. Beliefs about people who stutter
         (1) Traits and personality (e.g., shy or nervous)
         (2) Sources of help for stuttering (e.g., SLP, other stutterers, doctors)
         (3) Causes of stuttering (e.g., genetic, learned, act of God)
         (4) Life potential for stutterers (e.g., do well in school)
      b. Self reactions to people who stutter
         (1) Accommodating or helping stutterers (e.g., ignore stuttering, fill in words)
         (2) Social distance (e.g., concern if someone stutters) and sympathy (e.g., feeling pity)
         (3) Knowledge of and experience with stuttering (e.g., amount known about stuttering, friends or relatives who stutter)
         (4) Source of knowledge about stuttering (e.g., print, TV, personal experience)
      c. Obesity and mental illness
         (1) Overall impression
         (2) Want to have the condition
         (3) Amount known

3. Comparison values shown
    a. Profile shows means for sample(s) compared to the highest, lowest, and median samples in the archive so far
    b. Graphs show an overall stuttering score that is the mean of the scores for beliefs and self-reactions

D. Reliability
1. Test-retest: Same 32 respondents filled out 2nd prototype of *POSHA-E* (1-9 ratings) 2 weeks apart with no treatment (St. Louis, Lubker, Yaruss, and Aliveto, 2009)
    a. Compared test vs retest 1-9 ratings
        (1) Point-to-point agreement
            (a) 50% identical; 70-80% ± 2 scale units
        (2) Correlations
            (a) Stuttering and general items: R = .81
2. Test-retest: Same 25 respondents filled out 3rd prototype of *POSHA-E* (1-3 & 1-5 scales) 3 weeks apart with no treatment (St. Louis, Remley, & Hancock, in progress)
    a. More respondents to be added
    b. Compared test vs. retest ratings
        (1) Point-to-point agreement
            (a) 75% identical; 93% ± 1 & 99% ± 2 scale units
        (2) Correlations
            (a) Stuttering and general items: R = .80
3. Scale (St. Louis, Hancock & Remley, in progress)
    a. Same 24 respondents filled out 2nd and 3rd prototypes of *POSHA-E* two weeks apart with no treatment
        (1) More respondents to be added
        (2) Scales produce similar results
        (3) 3rd prototype slightly higher for stuttering items but lower for obesity and mental illness

E. Validity
1. Construct and concurrent validity
    a. Reliability study: *POSHA-E*s 2 weeks apart with no treatment (1-9 scale)
        (1) Non-neutral item changes…52%:48% positive:negative (52% no change)
    b. Studies attempting to change attitudes
        (1) SLP graduate students before & after classes on fluency disorders (1-9 scale) (Reichel & St. Louis, 2004, 2007; St. Louis, Reichel, Yaruss & Lubker, 2009)
            (a) Modest improvement in attitudes
            (b) More "positive" changes on Bipolar Adjective Scale (Woods & Williams, 1976)
        (2) Before & after talk on stuttering by a moderate-to-severe stutterer to high school students (1-9 scale) (Flynn & St. Louis, 2007)
            (a) Modest improvement in attitudes
        (3) Comparison of before & after talk on stuttering to high school students to video on stuttering plus video followed by a talk (1-5 & 1-3 scales) (Flynn, 2009; Flynn & St. Louis, 2009)
            (a) Talk alone: Dramatic improvement
            (b) Video alone: Moderate-substantial improvement
            (c) Video + talk: Additional improvement but not as much as from talk alone
2. Predictive validity
    a. Comparison of views of stuttering self-help leaders and SLP fluency specialists with other stutterers and normal speakers
        (1) 25 self-help leaders and 21 fluency specialists showed most "positive" attitudes (St. Louis & George, 2008)
        (2) 25 mostly mild stutterers from WVU lists
        (3) 35 self-identified stutterers on *POSHA-E* ("Me" checked for "People known who… stutter") had attitudes more similar to nonstutterers

F. Translation issues
1. Some *POSHA-E* translations not back-translated

a. Occasionally found incorrectly translated items
(1) Deleted those results
2. Avoided idioms and slang in English versions
a. Often hard to translate
(1) E.g., Flynn: "Stuttering caused by physical or emotional abuse"
3. Some items could not be translated well
a. E.g., "My younger child…" and "My older child…" could not be translated to Spanish
b. Those items combined to "My child…"
4. French/Turkish/Bulgarian back translation compared to original for errors/inconsistencies
a. Very few ambiguities and rare translation errors
5. Errors can occur in translations, back translations, or both
6. Language vs. culture study
a. 60 respondents each in Canada and Cameroon (St. Louis, Roberts, Lukong, and Freese, 2006; St. Louis & Roberts, in press)
(1) 30 Stronger/only English speakers
(2) 30 Stronger/only French speakers
b. Many similarities but differences mainly country (culture) related—not English vs French related
(1) Countries more different than languages
(2) USA control group more similar to Canadians than Cameroonians
7. In almost all cases, translations carried the same meanings, based on similar results
a. Confirmed our assumptions

G. Sampling issues
1. Type of sampling
a. Most pilot studies used convenience samples
(1) Exceptions
(a) Generalist SLPs and Fluency specialists random
b. Convenience vs probability sampling (Ozdemir, Topbas, & St. Louis, 2008; Ozdemir, St. Louis, & Topbas, in review)
(1) Several types of probability sampling
(2) Random likely impossible in most settings
(3) Stratified representative sampling likely most effective
(a) Carried out like most political opinion polls
(4) Investigation ongoing in Eskisehir, Turkey
(a) Convenience sample: 106 adults—2007 (Aydin, 2008)
(b) Two probability samples—2008 and 2009
(i) Used randomly selected schools in a randomly selected population area with 100,000 people to identify children and adults to fill out *POSHA*s
(a) Children, parents, grandparents (or aunt and uncles), and neighbors
(i) Desired gender of parent/grandparent according to child's odd/even birthday
(c) Compared 50 each from Eskisehir and a 2006 different Turkey sample with 50 neighbors in each Eskisehir probability samples
(i) Convenience samples younger, more educated, and higher relative income.
(ii) Convenience samples generally had better attitudes, but not for all items
(a) Overall stuttering scores similar but differences in subscores
(5) Similar school-based probability sampling strategy used in Kuwait for parents and teachers (Al-Khaladi, Lincoln, McCabe, Packman, & Alshatti, 2009; Abdalla & Al-Saddah, 2009)
c. Conclusions on type of sampling
(1) Task force expected that probability sampling will be necessary
(a) Likely true
(b) School-based sampling can work
(2) Inspection of all pilot study data suggests that convenience samples

are surprisingly robust
(a) Especially in general items, e.g., “overall impression” and “want to be”

H. Sample size
1. All but a few pilot studies used 20-100 respondents
a. Range (n = 7 - 424)
2. Not clear how many respondents needed
a. Recent data suggest small and large samples yield similar results (St. Louis, 2008)
3. From 2000+ respondents in archive
a. Samples of 200, 100, 50, 25 and 12
b. 3 replicates of “random”
(1) Sampled without replacement each time
c. 3 replicates of “stratified representative”
(1) Sampled representative number from each sample in archive, i.e., about every 10th respondent
(2) Smaller samples taken from the original selections
d. 3 replicates of “convenience” samples
(1) Located actual samples about the sizes of the previous probability samples
e. Findings
(1) Three sets of “random” and “stratified representative” samples much more similar than sets of “convenience” samples
(2) Larger “random” samples closer to overall mean than smaller “random” samples
(a) Sample sizes of 25 to 50 generally adequate
(3) Some *POSHA* items robust even with smaller samples
(a) E.g., general items

I. Item analysis
1. Goal to make *POSHA* user-friendly
a. Several criteria to retain or eliminate items
2. Factor analysis
3. Inspect pilot studies for
a. Differences and variability across samples
b. Difficulties in translation/interpretation
c. Changes in pre vs post samples for changes
d. Consideration of what stakeholders would want to know
(1) E.g., Where do respondents get their information about stuttering?
4. Factor analysis
a. 126 variables inspected from 2050 respondents from all three prototypes of *POSHA*
(1) Principal Components analysis with Varimax rotation and Eigenvalues >1
(2) Scree Test looked normal with 5-6 factors before beginning to level off
(3) Generated 35 factors
(a) Far more than most data sets but used correlations of ≥ .4 (color-coded on table)
(b) Looked at smaller correlations .2 - .4
b. Most factors can easily be named
(1) Very little overlap, i.e., most items only loaded on one factor
(a) Many factors related to attributes other than stuttering; not considered in item analysis
(2) Clearly identified related items based on correlation profiles
(a) Factor 1: Stuttering: likelihood of success at school or work
(b) Factor 2: Stuttering: psychological/learning cause
(c) Factor 3: Stuttering: concern for non-family contacts
(d) Factor 5: Stuttering: concern for family/self
(3) Identified redundant items
(a) Examples: “A person who stutters can…
(i) Interact with people socially” (R = .87)
(ii) Make friends” (R = .90)
(iii) Do well at school” (R = .90)
(iv) Get a job” (R = .90)

(v) Do well at work" (R = .87)
(vi) Raise a family" (R = .77)
(b) Strategy: choose one item for that factor, i.e., "make friends"

5. Other item analysis criteria
   a. Eliminated confusing and difficult-to-translate items
   b. Could items be changed?
      (1) Inspected pre-post samples
      (2) Strategy: select items that can be changed
   c. Consideration of what stakeholders would want to know
      (1) E.g., Where do respondents get information?
   d. Variability across pilot study samples
      (1) Inspected variability in 38 samples
         (a) General "want to be" items
            (i) Little variability except for old and stuttering (partly due to various samples with people who stutter)
         (b) Stuttering items
            (i) Some items variable (e.g., in emotions, comfort and pity most variable)
            (ii) Other items not variable
   e. Strategy: select both variable and invariable items

III. Progress, benefits, and challenges

A. Looking back
   1. 2001, we used a graphic for some purposes of IPATHA listing
      a. Good design
      b. Reliable and valid
      c. Other languages
      d. Quick and easy

B. Progress so far
   1. *POSHA-S* is user-friendly
   2. Developed a satisfactory rating scale
   3. Response time about 10 minutes (8-13)
   4. Order effects & errors in tallying minimal
   5. Pilot studies with "partners" (recruits & volunteers) successful with varied samples
   6. Robust translations into 10 other languages
      a. Non-native language questionnaires appear satisfactory (e.g., Denmark, Nepal)
   7. Very similar results from modest sample sizes (25-50) & larger samples
   8. Test-retest reliability & construct validity documented in 2nd & 3rd versions
   9. Similar & comparable results from different rating scales
   10. School-based probability sampling achieved
   11. Used with ages from 11-12 yr to elderly respondents
   12. Similar results with & without printed definitions of stuttering

C. Benefits so far
   1. Some global differences clearly documented
   2. Used successfully to measure a few planned efforts to change attitudes
   3. Attitudes for stuttering successfully compared to other attributes
      a. Increased sensitivity of instrument
      b. Possibility for wider scope with IPATHA
         (1) Obesity
         (2) Mental illness

D. Challenges
   1. Publish available pilot data
      a. I'll be busy!
   2. Promote research on attitudes
      a. International comparisons of public attitudes toward stuttering
         (1) *POSHA-S* can provide comparable data
      b. Systematic initiatives to improve public attitudes toward stuttering
         (1) Not as easy as many once thought
         (2) *POSHA-S* can help identify more vs less effective strategies
         (3) Determine predictors of attitudes
            (a) Usual demographic predictors have not been encouraging
            (b) Possibly study those who do/do not change in pre-post studies; those with very negative attitudes

3. Make *POSHA-S* available to stakeholders but assure its appropriate use & interpretation
    a. Develop policies & procedures for…
        (1) Translations
        (2) Human subject protection
        (3) Adding custom items
        (4) Paper-and-pencil vs online questionnaires
        (5) Tallying results & sending copies of results to add to & update the archive
    b. Develop succinct summaries
        (1) Final profiles, stuttering scores show promise
    c. Develop meaningful interpretations
        (1) Provide information stakeholders need
            (a) Their sample vs similar & all samples
            (b) Will require a large & growing archive
            (c) Likely will involve a fee to cover costs
        (2) Possibility: Determine progress relative to an "ideal environment" for stutterers
4. Possibility: What would an ideal environment for stutterers look like? Dimensions as goals
    a. *Enlightened*: having current and accurate knowledge about stuttering
    b. *Understanding*: able to understand and appreciate what the stutterer experiences
    c. *Accommodating*: willing and able to make allowances—when necessary—for stutterers
    d. *Assisting*: willing and able to help, offer advice, or support a stutterer
    e. *Sympathetic*: feeling genuine concern for stutterers
    f. *Accepting*: not being bothered by stuttering even when confronting it personally
5. I invite researchers, policy makers, self-help leaders, clinicians and others to contact me at <kstlouis@wvu.edu>

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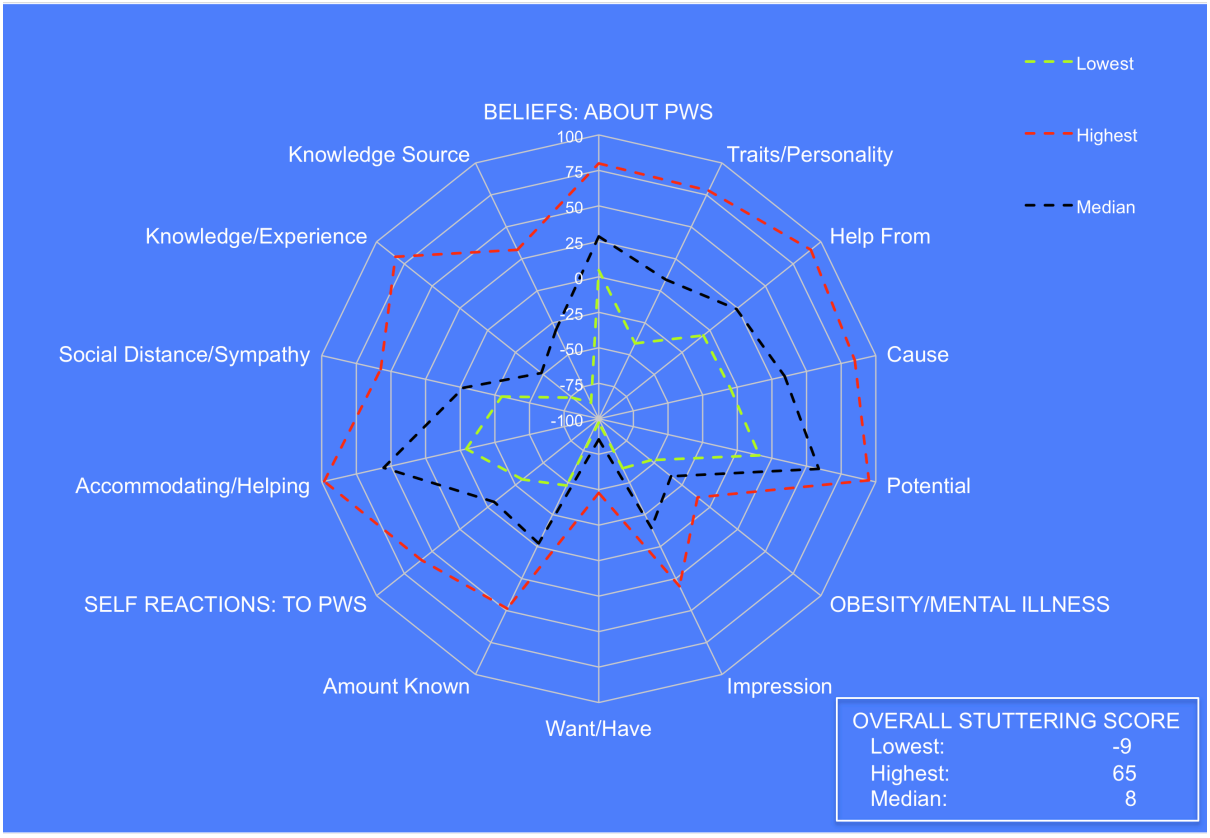

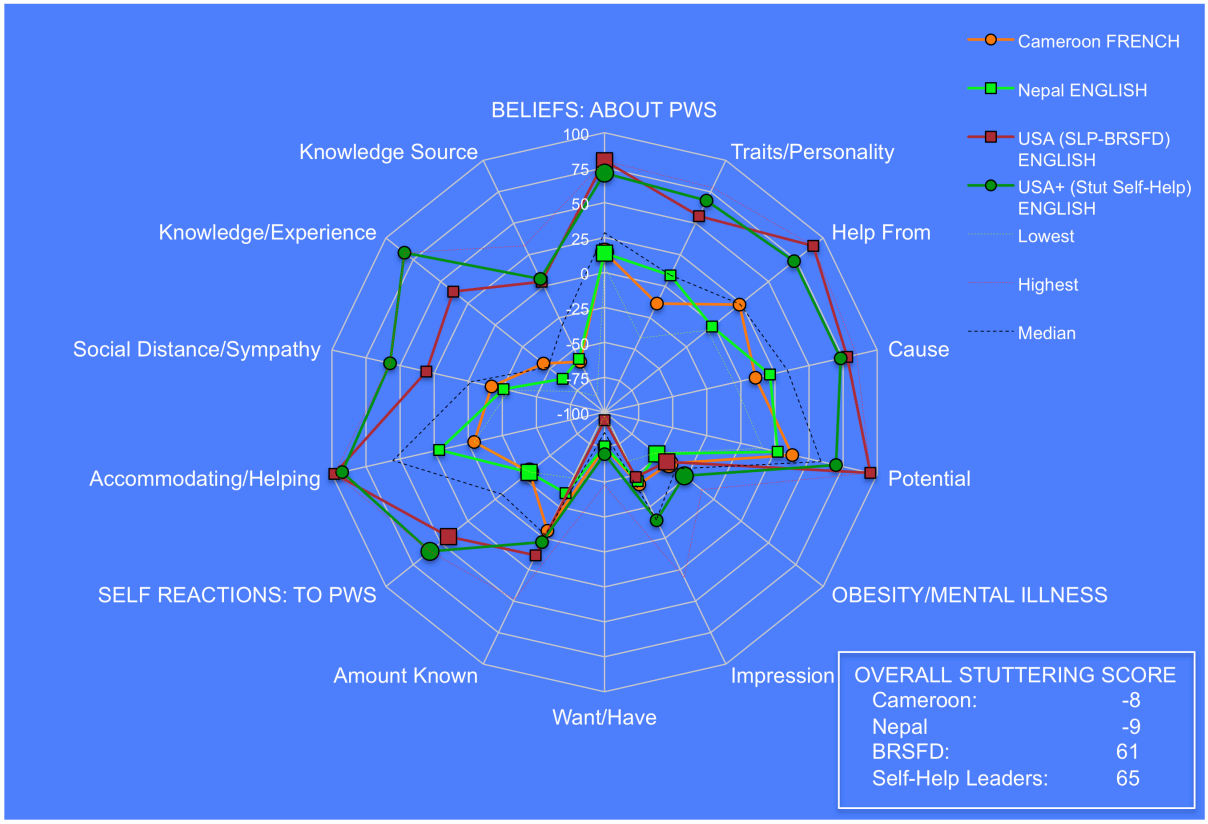
BELIEFS: ABOUT PWS
Traits/Personality
Help From
Cause
Potential
OBESITY/MENTAL ILLNESS
Impression
Want/Have
Amount Known
SELF REACTIONS: TO PWS
Accommodating/Helping
Social Distance/Sympathy
Knowledge/Experience
Knowledge Source
100
75
50
25
0
-25
-50
-75
-100
Cameroon FRENCH
Nepal ENGLISH
USA (SLP-BRSFD) ENGLISH
USA+ (Stut Self-Help) ENGLISH
Lowest
Highest
Median
OVERALL STUTTERING SCORE
Cameroon: -8
Nepal -9
BRSFD: 61
Self-Help Leaders: 65